



NEWS



The Newsletter of the Department of Veterans Affairs Richmond/Southeast Parkinson's Disease Research Education and Clinical Center

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Richmond/Southeast PADRECC Overview

By Miriam L. Hirsch, M.S., R.N., Associate Director of Education

In 2001, the Department of Veterans' Affairs (VA) created six Parkinson's Disease Research, Education and Clinical Centers (PADRECC) in an effort to deliver state of the art care for veterans suffering from Parkinson's disease. The centers are located in Philadelphia, Richmond, Houston, Portland, San Francisco and Los Angeles. Please refer to the PADRECC service area map on page 2.

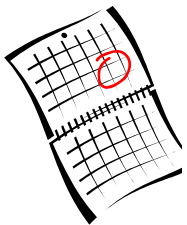
The Hunter Holmes McGuire VA Medical Center in Richmond, VA is home to the PADRECC for the southeastern region of the United States. Veterans who have received an honorable discharge from any branch of the United States armed forces and who have served on active duty either during wartime or peacetime are eligible to receive PADRECC services.

The PADRECC offers a variety of patient care services and research opportunities for veterans who have been previously diagnosed with Parkinson's disease or related disorders or have just started to notice symptoms. The PADRECC staff is comprised of experts in the field of neurology and more specifically in treating those with Parkinson's disease and related movement disorders. Please refer to page 4 for a list of staff.

Veterans have access to innovative strategies and treatment interventions to improve functional ability and life satisfaction. Furthermore, they have the valuable opportunity to participate in cutting edge research intended to lead to more effective treatments and ultimately to a cure for Parkinson's disease. Current studies include but are not limited to the success of deep brain stimulation in hard-to-treat patients, adult stem cell research, and clinical drug trials. More detailed information on this research and others is provided in this newsletter.

In collaboration with Virginia Commonwealth University Health System, participation in PADRECC clinical research is also available to non-veterans with Parkinson's disease.

Other PADRECC services include but are not limited to multidisciplinary assessment and treatment, clinical trials, physician consultation, medical management, surgical interventions, neuropsychological services, physical and occupational therapy, speech therapy, nursing services, caregiver resources, educational materials, community education programs, patient and family programs, support groups and programs to educate medical professionals. For more information about the Richmond/Southeast PADRECC services and research program, please call (804) 675 -5931 or toll-free (800) 784-8381 ext. 5931.



**SAVE THE
DATE!**

Parkinson's Disease Update 2003

*An All-Day Conference for
People with Parkinson's Disease
and their Caregivers*

SEE PAGE 4 FOR DETAILS

PADRECC Service Areas

Houston PADRECC
(713) 794-7841

Philadelphia PADRECC
(215) 823-5934 or toll-free (888) 959-2323

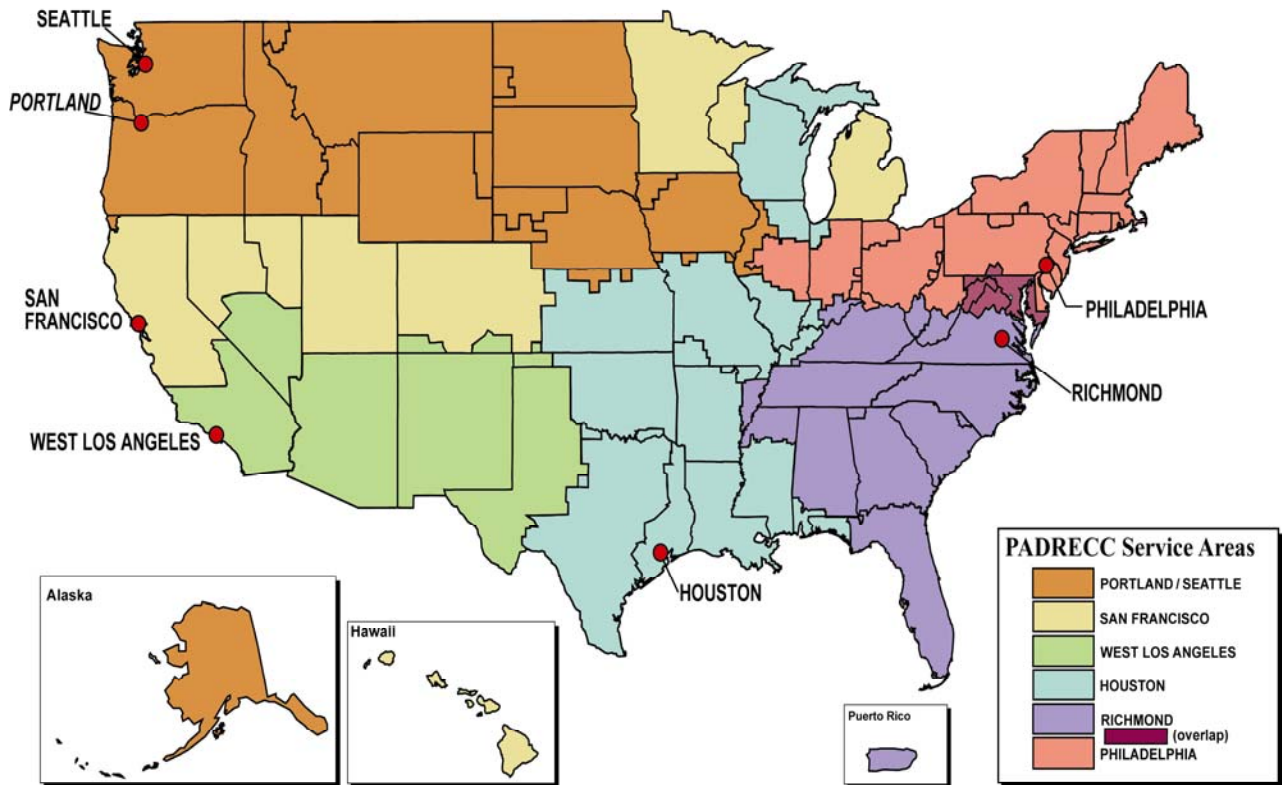
Portland/Seattle PADRECC
Portland: (503) 721-1091 Seattle: (206) 277-4560

Richmond/Southeast PADRECC
(804) 675-5931 or toll-free
(800) 784-8381 ext. 5931

San Francisco PADRECC
(415) 379-5530

West Los Angeles/Southwest PADRECC
(310) 478-3711 ext 48001

Recommended Service Areas for PADRECCs



Veterans Health Administration

Modified from an image provided by the St. Louis Employee Education and Resource Center



Richmond/Southeast PADRECC Contact Information

Hunter Holmes McGuire Veterans Affairs Medical Center
1201 Broad Rock Boulevard, Room 2C-114
Richmond, VA 23249

Phone: (804) 675-5931 or toll-free (800) 784-8381 ext. 5931

Fax: (804) 675-5939

Richmond PADRECC website: www.pdr.pmr.vcu.edu

National PADRECC website: www.va.gov/padrecc

Richmond/Southeast PADRECC Research

By Vincent Calabrese, M.D., Medical Director

A number of clinical trials are being conducted at the Richmond/Southeast PADRECC. These trials involve examining the effectiveness of several experimental treatments including medications and surgical interventions. Basic science research is also being conducted at the Richmond/Southeast PADRECC where theories about causes of Parkinson's disease are being tested. Research is an integral part of the Richmond/Southeast PADRECC and there are opportunities for veterans and non-veterans to participate. Several of the research studies will be discussed in this article.

A cooperative study involving all six PADRECCs is currently under way in which the effectiveness of deep brain stimulation (DBS) is being studied. More specifically, this research will try to determine what are the differences in the effects of two accepted brain targets in reducing symptoms. There is still much to be learned about DBS and what part of the brain is the most effective target. Dr. Katherine Holloway, the PADRECC Director of Surgery has described this procedure and the study in more detail on page 5 of this newsletter.

The purpose of the *PROGENI* clinical trial sponsored by the National Institutes of Health (NIH), is to identify genetic markers in siblings with Parkinson's disease. Hopefully this will enable the development of treatments aimed at reversing and preventing Parkinson's disease. The Richmond/Southeast PADRECC is one of the sites of this study.

Research is also being conducted at the Richmond/Southeast PADRECC that involves the physiology of the brain's electrical activity. The electrical activity in certain areas of the brain changes in Parkinson's disease. This area of research lead by Dr. Mark Baron, involves identifying areas of the brain that become overactive or under-active in Parkinson's disease and in other movement disorders. It is hoped that new treatment strategies can be developed as our understanding of the physiology of Parkinson's disease increases.

Clinical drug trials are an important component of the Richmond/Southeast PADRECC. The drug trials involve testing the effectiveness of new medications to treat the symptoms of Parkinson's disease and studies that evaluate diverse medications that have the potential to slow down or reverse the disease process. Please refer to the list of clinical trials currently being conducted at the PADRECC on page 7. The trials are sponsored by a variety of groups including the National Institutes of Health, individual pharmaceutical companies and the Parkinson's Study Group - which is an academic clinical trial consortium.

New studies are constantly coming forth at the Richmond/Southeast PADRECC. For more information about the PADRECC research program please call our center at (804) 675-5931 or toll-free (800) 784-8381 ext 5931.



PADRECC Support Group

There is a new support group for veterans with Parkinson's disease and their families. This group meets every 4th Thursday of the month from at 1:00-2:30 at Hunter Holmes McGuire VAMC in Richmond, VA. For more information about this group and/or others in your area or if you would like to start a group, please call Miriam Hirsch at (804) 675-6952 or toll-free (800) 784-8381 ext. 6952.

The Richmond/Southeast PADRECC Staff

In an effort to help improve the quality of care to veterans with Parkinson's disease and their families and to increase public awareness and understanding of this condition, the Richmond/Southeast PADRECC is staffed with many caring and knowledgeable people. The PADRECC team includes:

Vincent Calabrese, M.D.
Director and Neurologist

Kathryn Holloway, M.D.
Neurosurgical Director and Neurosurgeon

Ronald Seel, Ph.D.
Executive Director and Neuropsychologist

David Cifu, M.D.
Associate Director of Patient Care services and Psychiatrist

Mark Baron, M.D.
Associate Director of Research and Neurologist

Miriam Hirsch, M.S., R.N.
Associate Director of Education and Editor

Helen Fillmore, Ph.D.
Adult stem Cell Lab Director

William Carne, Ph.D.
Psychologist

Mariann Haselman, R.N., B.S.N., CNRN
Neurosurgical Nurse Coordinator

Peggy Roberge, R.N.
Study Nurse Coordinator

Nanette Eubank, R.N., CCRP
Neurosurgical Nurse Coordinator

Charles Blaine, M.S.
Clinical Research Fellow

Patrick Jehle, M.S.
Clinical Research Fellow

Jason Ong, M.S.
Clinical Research Fellow

Rashelle Brown, B.S.
Clinical Research Fellow

Judy Wade
Research Assistant

Cathy McGrady
Program Support Assistant

Parkinson's Update 2003

Patient and Family Symposium

The Richmond/Southeast PADRECC will be sponsoring an all-day conference for people with Parkinson's disease and their family caregivers on Saturday April 12, 2003 at the Holiday Inn-Koger Conference Center in Richmond, VA. A variety of topics will be presented aimed at improving one's level of understanding of Parkinson's disease and its treatment as well as the ability to cope with the challenges that this disorder causes.

Please call Miriam Hirsch at (804) 675-6952 or toll-free (800) 784-8381 ext 6952 to request a conference brochure.



Parkinson's Information

A variety of free educational materials including booklets, fact sheets, videotapes, and magazines are available through the Richmond/Southeast PADRECC lending library. In addition, our staff is available to answer questions about Parkinson's disease and its treatment.

Please call (804) 675-6952 or toll-free (800) 784-8381 ext 6952 if you need assistance.

Surgical Approaches in Parkinson's Disease

By Kathryn Holloway, M.D., Neurosurgical Director

In approximately 75% of people with Parkinson's disease, the medications used to control symptoms become less effective. Some may experience too little or too much movement. Others may not respond at all to the medications and/or may develop neuropsychiatric complications such as hallucinations. Surgical intervention may be appropriate for those patients whose medications are no longer effective in controlling the symptoms of Parkinson's disease or cause severe side effects.

Deep brain stimulation (DBS), a type brain surgery can be an effective treatment for reducing some of the symptoms of Parkinson's disease. During this procedure, an electrode is placed into a certain portion of the brain. This electrode is connected to a battery pack and is called a "stimulator" and looks very similar to a pacemaker. It functions like an "off" switch by interrupting the electrical impulses in certain parts of the brain that become over-active in Parkinson's disease.

The effects of the stimulator are reversible and can be changed or turned off by a trained healthcare professional. This adjustability and reversibility is a significant improvement over previous surgical techniques such as the pallidotomy and thalamotomy in which certain portions of the brain are destroyed (ablative) or permanently switched "off." An improvement in functioning can occur in both types of surgery although there are fewer complications associated with DBS. This makes it more beneficial to the patient.

The *subthalamic nucleus* and the *globus pallidus* are two locations in the brain that are targeted in the DBS procedure. Certain symptoms of Parkinson's disease can be reduced when these two areas are turned "off" by the stimulator. These include tremor, rigidity, slowness of movement, difficulty walking, and "freezing," as well as extra movements or dyskinesia that are medication side effects. The amount of daily "on" time in which the Parkinson's symptoms are better controlled can be increased as well.

The research shows that DBS results in a 40-60% improvement in symptoms as measured by a section

of the Unified Parkinson's Disease Rating Scale (UPDRS), a standardized rating scale. This is in contrast to patients who despite best medical therapy, are typically 5% worse off at the end of the year.

Additionally, patients who were treated with a pallidotomy experienced a 20-25% improvement in symptoms. Those who received fetal tissue transplants experienced an 18% improvement. Thus DBS appears to be the most effective surgical option in reducing Parkinson's symptoms at the current time.

Unfortunately, there is a 1-3% risk that the brain will be injured during the DBS procedure. As a result of this damage, patients may experience loss of speech, paralysis, coma or even death - usually caused by bleeding in the brain. There is also a 1-2 % risk of infection usually requiring the removal of the device.

DBS can be quite an effective treatment in those hard-to-treat patients who meet specific criteria. Patients who do not benefit from DBS are those who have Parkinson-like conditions but do not actually have Parkinson's disease. The best marker for this population is that they have never responded to the medication carbidopa/levodopa or Sinemet™. In addition, the DBS procedure should not be performed on patients with cognitive decline or changes in memory not related to the medication(s) because the symptoms may be worsened.

The electrodes must be placed precisely in the right area in the brain in order to have a desired effect. The DBS surgical procedure therefore requires special expertise. The evaluation and surgical procedure are conducted at the Richmond/Southeast PADRECC using a team approach with neurosurgery, neurology, neuropsychology and nursing staff. A combination of MRI imaging, microelectrode recording (listening to the electrical activity of certain brain cells) and test stimulation is used to achieve the best results. The patient is also an important member of the team. He/She is awake during the procedure and is asked

Continued on next page

Surgical Approaches Continued...

to interact with the examiner in an effort to determine if there is indeed improvement in the Parkinson's symptoms.

In order to achieve maximum benefit following the surgery, patients must come back for regular visits to the clinic to have the device programmed. They generally continue to take medication, although the dose may need to be adjusted following surgery.

The Richmond/Southeast PADRECC is currently involved in a clinical trial to evaluate which of two locations used for DBS (the globus pallidus or substantia nigra) is better for any group of patients and how that compares to the best medical therapy. The DBS procedure is also available to those who do not wish to participate in the clinical trial.

For more information about DBS or the PADRECC clinical trial please call Mariann Haselman or Nanette Eubank, neurosurgery nurse coordinators at (804) 675-6284 or toll-free (800) 784-8381 ext 6284.



Parkinson's Disease Resources

There are several national organizations for Parkinson's disease. The APDA and NPF are two such groups that offer a variety of educational materials and programs, as well as information about support groups and other support services. For more information please call our center or the organizations below:

American Parkinson Disease Association (APDA)

*National Office (800) 223-2732

www.apdaparkinson.com

*Closest APDA Information and Referral Center
(888) 400-2732

National Parkinson Foundation (NPF)

(800) 327-4545

www.parkinson.org

What is a Vet?

*Reprinted with permission from Richmond Times-Dispatch
This editorial first appeared in 1995*

Some veterans bear visible signs of their service: a missing limb, a jagged scar, a look in the eye. Others may carry the evidence inside them: a pin holding a bone together, a piece of shrapnel in the leg – or perhaps another sort of inner steel: the soul's alloy forged in the refinery of adversity. Except in parades, however, the men and women who have kept America safe wear no badge or emblem. You can't tell a vet just by looking. *What is a veteran? A veteran is*

...the cop on the beat who spent six months in Saudi Arabia sweating two gallons a day making sure the armored personnel carriers didn't run out of fuel.

...the Nebraska farmer who worries every year that this time the bank really will foreclose.

...the bar room loudmouth, dumber than five wooden planks, whose overgrown frat-boy behavior is outweighed a hundred times in the cosmic scales of four hours of exquisite bravery near the 39th parallel.

...the nurse who fought against futility and went to sleep sobbing every night for two solid years in Da Nang.

...the POW who went away one person and come back another –or didn't come back at all.

...the Quantico drill instructor who never has seen combat---but who has saved countless lives by turning slouchy no-counts into soldiers, and teaching them to watch each other's backs.

...the parade-riding legionnaire who pins on his ribbons and medals with a prosthetic hand.

...the career quartermaster who watches the ribbons and medals pass him by.

...the anonymous heroes in the Tomb of the Unknowns, whose presence at Arlington National Cemetery must forever preserve the memory of all the other anonymous heroes whose valor died unrecognized with them on the battlefield or in the ocean's sunless deep.

...the old guy bagging groceries at the supermarket --- palsied now and aggravatingly slow ---who helped liberate a Nazi death camp, and who wishes all day long his wife were still alive to hold him when the nightmares come.

...the ordinary and yet extraordinary human being---a person who offered some of his life's most vital years in the service of his country, and who sacrificed his ambitions so others would not have to sacrifice theirs. He is a soldier and a savior and a sword against the darkness, and he is nothing more than the finest, greatest testimony on behalf of the finest, greatest nation ever known.



PADRECC Research Studies

The following research is currently conducted at the Richmond/Southeast PADRECC:

Deep Brain Stimulation (DBS)

The purpose of this study is to evaluate the outcome of deep brain stimulation as compared to the best medical therapy in hard-to-treat patients with Parkinson's disease. The study will also examine the effectiveness of stimulating certain targets in the brain.

Frameless Stereotaxy for Deep Brain Stimulation

Before deep brain stimulation surgery, a *stereotactic frame* - a large metal ring that encircles a patient's head and face- is attached to the skull with pins. This device allows for the accurate placement of instruments within the brain during the procedure although there are several disadvantages. A new frameless stereotaxy device has been developed as a result. Its effectiveness is currently being examined in this study.

Adult Stem Cell Research

There is evidence to suggest that stem-like cells are located in certain parts of the adult brain. These cells are currently being collected from patients who have undergone certain epilepsy surgeries as well as from post-mortem adult brain tissue. The objectives of this study is to learn more about these cells, determine how to best grow them and what effects they have when transplanted into a rat model of Parkinson's disease.

Laboratory Investigations of Dystonia

Investigations of a number of experimental animal models of Parkinson's disease, dystonia and Tourette's syndrome are underway and specific patterns of abnormal brain signaling associated with these conditions have been identified. It is hoped that these investigations will lead to the development of better medical strategies aimed at reversing the abnormal brain signaling that is contributing to these disorders.

The Impact of Gait Training on People with Parkinson's Disease

The focus of this research project is to learn about the gait control of people with Parkinson's disease through an investigation of how they walk and to examine the effects of visual and auditory cues.

Pain in Parkinson's Disease

In as many as 50% of people with Parkinson's disease, pain is reported as a major problem. Despite this finding, pain in Parkinson's disease is poorly understood. The purpose of this study is to better understand what causes pain in Parkinson's disease and its impact on quality of life.

Visual Motor Study

The ability to control one's eye movements appears to be affected in Parkinson's disease. The loss of ability to adequately control eye movement can certainly limit normal day-to-day activities such as driving and reading. The goal of this study is to examine the effects of Parkinson's disease on eye movement and to determine the relationship between head and eye position while reading.

PROGENI

This study is sponsored by the National Institutes of Health (NIH) and its purpose is to identify genetic markers in siblings with Parkinson's disease.

PRESTO

The purpose of this study is to examine the effectiveness of rasagiline mesylate, an experimental medication, in people with advanced Parkinson's disease.

Rotigotine Patch Study

This study involves examining the effectiveness of rotigotine, a new dopamine agonist in people with early stage Parkinson's disease. This medication is administered in the form of a skin patch.

FUTURE STUDIES:

We hope to offer several new clinical trials in the near future. These trials include but are not limited to examining the effects of several neuroprotective medications, the impact of exercise and tai chi, the incidence of melanoma in Parkinson's disease, and the benefits of speech therapy in Parkinson's disease.